

April 16, 2013

The Honorable Fred Upton
Chairman
Committee on Energy and Commerce
U.S. House of Representatives
Washington, DC 20515

The Honorable Joe Pitts
Chairman
Subcommittee on Health
Committee on Energy and Commerce
U.S. House of Representatives
Washington, DC 20515

The Honorable Michael Burgess
Vice Chairman
Subcommittee on Health
Committee on Energy and Commerce
U.S. House of Representatives
Washington, DC 20515

Dear Chairman Upton, Chairman Pitts, and Vice Chairman Burgess:

The rare disease patient community greatly appreciates your leadership in offering a solution to the funding issues associated with the Preexisting Condition Insurance Plan (“PCIP”) Program and strongly supports swift passage of H.R. 1549, the Helping Sick Americans Now Act. The prohibition against preexisting condition exclusions that the Affordable Care Act (“ACA”) established is one of several vital insurance market reforms that will ensure patients with life threatening and debilitating, chronic rare diseases will have access to their treatment regimen. The PCIP program is a critically important component of the ACA market reforms because it affords those patients that currently lack insurance coverage due to these discriminatory practices an opportunity to enjoy temporary coverage until they can transition to meaningful coverage on January 1, 2014.

The decision in February to suspend PCIP enrollment could have catastrophic consequences for the rare disease patient community because of treatment delays. Impediments to accessing rare disease therapies not only lead to poor health outcomes, but also drive up health care costs due to increased physician office visits, emergency room interventions, hospital admissions, and surgical interventions. In order to ensure patient access, we strongly support your efforts to:

- **Protect program solvency for existing PCIP beneficiaries:** The Department of Health and Human Services (“HHS”) has not disclosed how much of the \$5 billion in funding remains for more than 100,000 currently enrolled PCIP beneficiaries. The anxiety resulting from this uncertainty is troubling for a subset of the population who has already had to overcome significant challenges in obtaining proper diagnosis and finding a viable therapeutic option. Additional program funding will remove any uncertainty that the program remains solvent for the remainder of 2013.

- **Lift the enrollment suspension:** Due to the eligibility requirement of being uninsured for six consecutive months prior to PCIP enrollment, there are thousands of patients who would have been eligible to enroll in PCIP after the suspension dates of February 16th (Federal PCIP) and March 2nd (state-operated PCIP). Removing this condition and providing more funding would save and improve the lives of thousands in the rare disease community by affording them access to immediate coverage until they can transition to new coverage in January.
- **Provide safeguards to ensure a smooth transition to coverage:** The statute requires HHS to develop procedures to transition PCIP beneficiaries into the qualified health plans offered in the Affordable Insurance Exchange. The rare disease patient community is very concerned that HHS has not taken such action, which is especially unsettling in light of the fiscal health of the PCIP program.

Due to our relatively low number of patients per condition, the rare disease community is often overlooked when policies are being negotiated on Capitol Hill or implemented by HHS. Providing additional funding not only to sustain the PCIP program for the remainder of 2013, but also to give more uninsured patients with preexisting conditions the opportunity for immediate coverage will demonstrate a strong commitment to the rare disease patient community. Thank you for your support.

Sincerely,

Adult Congenital Heart Association
Alpha-1 Association
Alpha-1 Foundation
CADASIL Association
COPD Foundation
GBS/CIDP Foundation International
Global Genes
Hemophilia Federation of America
Hereditary Angioedema Association
Immune Deficiency Foundation

Lipodystrophy United
Little Miss Hannah Foundation
The Mastocytosis Society
MLD Foundation
National Gaucher Foundation, Inc.
National MPS Society
National PKU Alliance
Noah's Hope for LINCL-Batten Disease
Platelet Disorder Support Association
United Leukodystrophy Foundation

cc: The Honorable Henry Waxman
The Honorable Frank Pallone